

OUR NEWS

Oxford and District Branch
quarterly newsletter

Chair's Chat: Sally Bromley

Since our last newsletter I have been preparing for the conference, Parkinson's 200 Plus. Nothing prepared me for the amount of work it generated. Chrystalina Antoniades from Oxford University, who many of us know, Patrick Lewis from Reading University, who has spoken at our meetings and Kevin McFarthing our research officer, were the team who produced not only the conference but also talks at two prestigious Oxford Institutions plus a display.

All this was sandwiched together with other events. Nigel and Debbie's cycle ride 'Going North' kicked us off in mid August. In early September there was the Oxford Walk. Then the weekend before the conference there was BOXCAM – a 200 mile cycle ride from Bristol to Oxford for an overnight stay, then up at 6am for the next 100 miles to Cambridge thus linking three main research centres. Greeting the cyclists as they arrived at the hotel was an honour. With Debbie and Nigel on hand who understood what a long cycle ride is all about there were smiles of relief all round.

Our BBQ at Wytham Woods was again a success with the rain falling right on cue just as we were about to serve! It didn't dampen our spirits and a good time – and feast – was had by all. Thanks to the Appleton Family.

I'm sure many of us are nervous about 'web-browsing'. Our website is quite accessible and should provide us all with up to date information. Please tell us what you'd like to see. Having never had our own website before this is a big moment as we leap into the twenty-first century!

I am always keen to support younger people. So I am pleased to report that we now have a group of younger people who have been diagnosed with Parkinson's. I hope they can support each other in future.

The committee is concerned we have grown out of our current meeting hall and we are actively seeking suitable premises. Do get in touch if you know of anywhere that is close to the ring road has good car parking and more than the eighty seats we are using at the moment. The WI hall has served us well for many years but we have outgrown it.



Autumn 2017

NEW MEMBERS

A warm welcome to :

Andrea Harvey
Jon Hunt
Sue & John Monnery
Hazel & Ian Moodey
Nick Wrigley
Patricia Ball

We are sad to record the death of John Quertarman
Our sympathy to Margaret & family



HEALTH AND WELLBEING

by Sally Bromley

oxford.sally@gmail.com

01865 311302

Message from Age UK Oxfordshire

Our Strength & Balance classes are going from strength to strength (no pun intended!) and we currently have 10 across the county.

The very exciting news is that we launched our brand new Big Bold and Balance - Parkinson's exercise DVD at the Parkinson 200 conference last Monday in Oxford. If you are living with PD and live in Oxfordshire, please get in touch and we will be happy to send you a complimentary copy.

For further information on the Parkinson's UK Oxford branch please follow the following site.

www.parkinsons.org.uk/local-support-groups/regions/south-england/oxford-and-district-branch

Some of our newer classes this term are -

Cherwell	Bicester Methodist Church	Strength & Balance - Falls Prevention	Monday	1.30 – 2.30pm
City	Jericho Community Centre	Strength & Balance - Falls Prevention	Friday	10.30 – 11.30am
City	Marston Scout Hut	Strength & Balance - Falls Prevention	Thursday	11 – 12pm
South	Long Wittenham Village Hall	Strength & Balance - Falls Prevention	Wednesday	3.30 – 4.30 pm
South	Stortton Lodge, Goring	Strength & Balance - Falls Prevention	Monday	10.30 – 11.30 am
Vale	Grove Village Hall	Strength & Balance - Falls Prevention	Monday	4.30 – 5.30 pm (new time!)

Mindfulness for People with Parkinson's

By Azize Stirling

Research is showing that stress has a significant role in neuro-degeneration and depression in Parkinson's disease. Some studies find that non-motor symptoms like depression, anxiety, emotional dysregulation, cognitive impairment, and apathy, can have a far greater impact on disease progression, and health related quality of life, than motor symptoms.

It can sometimes be hard to recognise the stress in our lives, as in today's world it is part of the air we breathe. Mindfulness can teach people how to recognise stress. A programme in mindfulness can give us the time we need to step outside the lives we lead - time for just being and time for learning new life skills and consolidating old ones. We need time to develop a less reactive way of being, and to develop a kinder and wiser way of relating to what life throws at us. Mindfulness starts from the premise that we all experience distress and discomfort and all have the capacity for joy and well-being, even in the midst of challenge and difficulty.

There will be an Introduction to Mindfulness for PwPs workshop. The next available time will be Tuesday, October 31. Please contact Azizé Stirling on 01865 790168 or azize@onetel.com for more details.

This is a link to an article written by Jon Kabat-Zinn, the man credited with starting the secular mindfulness movement, on the event of the All Party Parliamentary Committee's report on the policy implications of mindfulness 'Mindful Nation'

<https://www.theguardian.com/commentisfree/2015/oct/20/mindfulness-mental-health-potential-benefits-uk>

Our very own Parky-fest!

This has been an exciting couple of months!

I had been searching for events to commemorate the publication of the Essay by James Parkinson but they were all research feedback and nothing specially for PwPs. Our own conference -Parkinson's 200 Plus – along with other events, has shown that people living with Parkinson's wanted a conference for themselves.

On September 18th in the Wesley Memorial Church 230 people came to listen to professionals, practitioners and people with Parkinson's. We heard about the progress of the condition over the last 200 years and also about up to date research from Oxford University. Finding out about the value of exercise is not fresh news for us but having it supported with proven data was interesting.

The second half was about living well with Parkinson's. Alex Reed had flown from Italy to inform us of the 4 pillars, Jim Sheridan explained his self monitoring process and Michele Hu told us of up and coming research projects. All our speakers were most interesting. But nothing prepared us for the small figure of Emma Lawton aged 33 telling us of her experience of living with Parkinson's in such a positive and amusing way while her neck was supported with a neck brace due to her dystonia. This was truly inspirational and an example to us all. Finally our own Paul rounded off the day with his humorous anecdotes of Parky stories!

The Bodleian Library became interested in the bicentenary and put up a display of James Parkinson's publications. They gave us the use of their lecture theatre and we were fortunate to hear Prof Brian Hurwitz tell us more about this fascinating man. On Oct 5th Cherry Lewis will talk about the Enlightened Mr Parkinson at the Natural History Museum which generously allowed us to use their lecture theatre.

To have come through these events and to have had fun on the way is good fortune. I am pleased have shared it with so many, and especially so many members from the branch. Thank you for your support and kind emails.

BRANCH PICNIC AT BLENHEIM PALACE

On Monday 10th July we held our first Branch Picnic at Blenheim Palace. It was much enjoyed and we hope that it will be possible to repeat it in future years. The weather was quite fair and the location was very pleasant. About 40-50 members took part and brought a delicious selection of savouries and cakes which went down very well with everyone who came.

The Palace had made a generous offer of providing the location free of charge and also giving Branch members a discounted rate for the house tour. We weren't really able to take advantage of this as there had been an exercise class earlier in the day and people couldn't get there until just before teatime. If we arrange to go again it would seem to be better to have a lunch time picnic. We could also arrange for some tea, coffee and cold drinks (perhaps paid for out of Branch funds?) using the facilities of the café in the Pleasure Gardens. The staff were particularly welcoming and helpful during our visit this year and if drinks were to be provided by them it would save people a lot of time worrying about preparing and carrying their own drinks.

Nigel Hamilton



FUNDRAISING

by Kit Marriott

kit@kitmarriott.com

This year the Oxford Walk took place on September 10th with approximately 200 registered walkers. Marshals and willing helpers, provided by our Oxford Branch, were in abundance. The many walkers were grateful for the cakes, provided by members, on their return to base. Income to date is an encouraging at £30,000 and should keep increasing over the coming months as pledges and sponsorship comes in.

The Walk committee will be discussing the future challenge of getting more than 200 walkers and whether boredom with the similar route might effect this issue. If you have suggestions for a different and interesting route please let Malcolm, Kit or Sally have your ideas. This year Malcolm Benson has efficiently and energetically taken care of the liaison between our Oxford Branch and PUK for which we are most grateful.

During August Nigel and Debbie Hamilton courageously and generously gave their time and effort to cycle from Oxford to Durham to Nigel's old University College, raising over £3000 for our Branch. Richard and Rachel held a charity day in support of the Branch so far collecting over £450. These local gestures are usually successful and beneficial to us as well as being rewarding for the organisers.

A Bridge day is being held for our benefit in Abingdon at the town's Bridge Club in October. In November there will be a coffee morning and the Marriotts are running a Bring and Buy from 10.30 to 12.30 on Saturday November 9th at the Artcafe in Whitchurch on Thames. Our Christmas Cards should be on sale there .

There will have been mention elsewhere within the Newsletter about the success of the Parkinsons 200 Conference, masterminded by our energetic Chair Sally. This explained so much about Parkinsons over the last 200 years, and doubtless will have raised a little money for us as well as allowing PwP's to share their experiences .

The Branch Barbecue held in Wytham Woods in August generated some useful income and was enjoyed by over 65 members thanks to professional cooking from the Appleton's supportive family.

FINANCIAL SNAPSHOT

by Carys Redmond our Treasurer

The branch has had a busy summer with some great fundraising from members including the Bensons and Walsh's donations from their wedding anniversaries and several coffee mornings together with one of the highlights on the social calendar of the Summer BBQ. In addition to this, the branch has now received the first tranche of money from its second legacy which was generously left by Ms Doreen Lewis. This money is being used to subsidise travel costs for those wishing to attend the European Parkinson Therapy centre in Italy. Further details are available on the website at <https://oxfordparkinsons.org.uk/classes.htm - exercise>

The branch continues to offer and subsidise a broad range of activities including 30 hours of free respite care from Bluebird, Voice classes, mindfulness classes and subsidises physio classes across Oxfordshire

THE HAMILTONS ARE BACK FROM THE BIKE RIDE NORTH

We completed our cycle ride up to Durham on 1st September, returning by train a couple of days later. When we got back to Oxford we were surprised to find how many people had been following our daily "blog" (we heard of one blog reader in Greece) and even more impressed by the very generous donations that had already been made. We had set a target of £1,000 to raise for the Branch and by the middle of September the total had reached more than £3,000. The "Blog" has now been revised to follow the journey in the right order [bit.do/gonorth].

Although there were a couple of minor disruptions to the plan we had devised, we generally reached each day's destination in time to relax before getting something to eat. One such disruption involved an encounter which Nigel had with a hedge by the tow-path alongside the Coventry canal. The route we had planned was full of variety, some rural and some urban. One of the things we discovered was just how satisfying it is to get up in the morning and set off with only one objective: to reach the next destination in one piece.

We discovered that most of our rural routes were quiet as we traversed the landscape on cycle paths, country roads, disused railway tracks and on paths beside fields. Our experience of the roads in cities (Coventry, Sheffield and Leeds for example) was very different but stimulating. Some of the most tranquil places, like the North Yorkshire Moors and the Tissington Trail running from Ashbourne to Buxton reminded us that much of our country is still unspoilt and as beautiful as it always has been.

The whole of the cycle ride was very good though it was quite tough at times and as the group of 18-20 year old lads who we met in Haswell, in County Durham, put it, we were probably "bonkers" to bicycle all that way.

Our best moment? Quite possibly being welcomed by our friends Nick & Ann in Whiteley Woods in Sheffield, or cycling in glorious sunshine from Felixkirk to Osmotherley in North Yorkshire. Or maybe when we cycled up the steep cobbled streets leading to Palace Green, and being welcomed, in Grand National style with Durham Cathedral as a backdrop, by our daughter Sarah with balloons spelling out the miles.

Nigel & Debbie Hamilton

Rachel and Richard Hawes coffee morning combined with the Tour of Britain

On 9th September Rachel and Richard Hawes held a coffee morning on the village green in Horton Cum Studley to coincide with the Tour of Britain Cycle Race as it was coming through the village.

This raised an amazing £441.20

In the photo are Rachel Hawes, Lisa Mynheer and Ruth David



BIG NEWS

THE OXFORD BRANCH GETS ITS OWN WEBSITE!

Many of us nowadays get much of our day-to-day information from websites. Wouldn't it be a good idea, we asked ourselves, if the Oxford Branch could make all its information available online? So it was that I, your Chair's husband and general digital dogsbody, set to work.

Three months on and we have our website – far from perfect, far from complete, a work in progress, but (I hope) already useful nonetheless. If you haven't already done so, please take a look the next time you're online:

oxfordparkinsons.org.uk

What else can we provide on the website to serve our members and visitors? Let us know what you think should be our priorities so that we can direct the available effort where it will be most useful. Some of the ideas that have been proposed include:

- an open discussion forum so that members can post messages and questions, and other members can reply and continue a discussion
- a library of hints, tips, suggestions and resources that we could build up over time, with members sharing experiences of what they find helpful and how they manage their Parkinson's
- the option to subscribe to occasional emails to get notifications of changes to the website content
- audio and video recordings of the presentations and discussions at Branch meetings

Finally, I would like to thank the many people who have already provided valuable and thoughtful feedback. Keep the criticisms coming to help us improve the website! Your comments, corrections, suggestions and new information can be sent by email to admin@oxfordparkinsons.org.uk or by contacting any Committee member.

Jonathan Bromley



RESEARCH NEWS

By Dr Kevin McFarthing

CAN WE STOP THE RATE OF DECLINE?

At the moment, there are no proven therapies that can stop or slow the progression of Parkinson's. However, there has been a lot of excitement in the Parkinson's world with the recent publication in the Lancet of a paper on the use of exenatide, a drug normally used in type 2 diabetes. The authors showed a decline in the UPDRS scores of those people taking exenatide, whereas the scores of those on placebo increased. The effect was sustained 3 months after the drug was stopped¹.

Voyager Therapeutics in the US have published interim results from a trial of a gene therapy treatment. It delivers a gene for an enzyme that helps to make dopamine, to a part of the brain that is starved of it in PD². Again, they showed a significant reduction in UPDRS scores, which was greater at higher drug doses. This was a smaller trial than that for exenatide, and may not prevent eventual loss of dopamine neurons. While there is still much work to be done, both of these results are very encouraging.

NEW DELIVERY METHODS FOR LEVODOPA

I started the last research update by saying that Levodopa is still the gold standard treatment for Parkinson's, more than fifty years after its introduction. What hasn't changed much is how we take it – tablets or capsules. This time I'd like to describe some work with new delivery methods.

There are two issues with standard Levodopa – how long it takes to start working; and how long it lasts. You may be familiar with people who use asthma inhalers. Using these devices gets a drug to the lungs, where it gets quickly into the bloodstream. Acorda Therapeutics in the US have developed Inbrija, a new Levodopa inhaler, phase 3 trials of which showed some effects starting only ten minutes after administration. They have submitted a New Drug Application to the US Food and Drug Administration and they're aiming to submit in Europe by the end of this year³.

Extending the working life of Levodopa is also important. Impax Pharma in the US has launched Rytary, with an effective duration of 4-5 hours⁴. Intec Pharma are developing an "Accordion Pill" which stays in the stomach, gradually releasing Levodopa and Carbidopa, showing a reduction in OFF time of 45% in Phase 2 trials⁵.

Neuroderm (now part of Mitsubishi Tanabe) have developed a device that gives continuous transdermal delivery of levodopa and carbidopa. They have completed Phase 2 studies showing that around 40% of patients in the study had no OFF time. Again, these results are from a small trial, but it should be a very easy decision to move to much larger Phase 3 trials⁶.

β2 ADRENORECEPTOR AGONISTS

β2 adrenoreceptor agonists are well established in the treatment of respiratory problems like asthma. Work in a newly-published paper has shown that people using them have a 35% reduction in the incidence of Parkinson's.

Previous work in the lab had shown a reduction in the amount of alpha-synuclein (a baddie in PD) produced by cells treated with one of these drugs. The scientists then analysed the Norwegian Prescription Database, and came up with the significant finding on disease incidence. They also found that drugs which block the β2 receptor, like propranolol, increased the risk of Parkinson's.

This has sparked a lot of interest in drugs like salbutamol, a β2 agonist. Early days still, but very interesting nonetheless, especially because these drugs have been in use for so long⁷. The next step needs to be a randomized controlled trial.

CAFFEINE

Observational studies like the one above, while exciting, still need to be proven in well-designed clinical trials. These don't always confirm the population association. For example, many studies had associated an increased consumption of coffee with a lower risk of PD. So, a group in Canada performed a randomized, controlled trial to actively assess the impact of caffeine on PD symptoms. An interim analysis showed no difference between caffeine and placebo, except for a decrease in daytime sleepiness (no surprise), a slight increase in dyskinesia and a slight decline in cognitive performance⁸.

This study again confirms the caution needed whenever association data are used to draw conclusions, without having evidence from randomized controlled trials.

1. [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(17\)31585-4.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(17)31585-4.pdf)
2. <https://scienceofparkinsons.com/2017/09/07/voyager-therapeutics-phase-ib-clinical-trial-results/>
3. <http://ir.acorda.com/investors/investor-news/investor-news-details/2017/CVT-301-Phase-3-Data-Showed-Significantly-Improved-Motor-Function-During-OFF-Periods-in-Parkinsons-Disease/default.aspx>
4. <https://rytary.com>
5. <http://intecpharma.com/pipeline/ap-cdld/>
6. <http://ir.neuroderm.com/phoenix.zhtml?c=253749&p=irol-newsArticle&ID=2283298>
7. <https://scienceofparkinsons.com/2017/09/02/beta2-adrenoreceptor-agonists-another-game-changer/>
8. <http://www.mdsabstracts.org/abstract/caffeine-as-a-treatment-for-parkinsons-disease-a-randomized-controlled-trial-cafedp/>

COMING UP...

OXFORD AND DISTRICT BRANCH MEETINGS, TALKS AND OUTINGS

OXFORD BRANCH MEETINGS

On the 1st Wednesday of each month at
Botley WI Hall
North Hinksey Lane OX2 0LT
Talks on general & medical topics
Group discussions

Winter Programme 2017-18

Nov 1	Quiz Night
Dec 6	Branch Christmas Party: Please bring a plate of food to share. Drinks provided.
Jan 3	Up to date with research: Dr Kevin McFarthing, committee member of our Branch, will bring us up to date with progress and prospects for the New Year.
Feb 7	Lysosomes and Enzymes: New research that our funds have helped to get under way. Professor Frances Platt and her assistant Mylene Huebecker will talk about their progress so far.
Mar 7	Branch AGM followed by cheese and wine

OTHER EVENTS

Oct 19	Bridge Evening, Abingdon
Dec 9 10.30-12.30	Art Cafe Coffee Morning at Whitchurch-on-Thames

ACTIVITIES

Zumba, Physiotherapy, Voice, Dance for Parkinson's (Ballet with ENB) and other activities; outings & holidays

FUNDING CARE & RESEARCH

We continue to support people with Parkinson's in our area and some of the research being conducted in Oxford as part of The Oxford Parkinson's Disease Centre

200 CLUB

£12 per year buys chances to win £25 or £12.50 at each monthly draw.
Malcolm Benson 01865 873843 runs it.
Call Malcolm to enter.

For full up-to-date information, visit
www.oxfordparkinsons.org.uk

BRANCH COMMITTEE

Chair
Sally Bromley 01865 311302
email oxford.sally@gmail.com
Secretary
Pen Keyte 01865 556032 / 0788943722
email oxfordparkinson@gmail.com
Vice Chair
Jem Appleton 01491 837331
Fundraiser
Kit Marriott 01189 844582
Treasurer
Carys Redmond 07817 597623
Membership
Diana Townsend 01865 751362
Research News
Kevin McFarthing 07802 25618
Media & Publicity
Paul Mayhew Archer
Programme
Nigel Hamilton.
George Philip, David Salisbury,
Martin Tims and Jenyth Worsley

TAXIS

Talk to Lin on 01235 520573, if you cannot get to a branch meeting, this is a one off emergency aid.

PARKINSON'S 200 PLUS



On 18th September our Branch staged a half-day conference in Oxford where carers, people with Parkinson's and professionals learnt more about living with the condition and the latest research into a cure.

